



SW Florida Myositis KIT Newsletter

We Care, So Come and Share!

Published Quarterly

May, 2014 Edition

May 3, 2014 Meeting

We had 34 in attendance, including two first-timers and their partners

Please note there are two other documents following this newsletter. Don't miss them!

“...possibly our best speaker yet...”

That's what one attendee said about Dr. Myma Albayda, from the Johns Hopkins Myositis Center, our featured speaker at this meeting. There were 34 of us in attendance, including first timers: Kim Kronfeld (DM) and her friend, Norrine Maslanka and Judy Lewis (DM) and her partner Ed Lewis.

Dr. Albayda addressed all three myositis diseases and reviewed how they are diagnosed and treated. She also spoke about the related autoimmune antibodies and what they might mean to our doctors and us. Of particular interest to many of us was her insight into what patients might expect if they come to the Hopkins center. She was kind enough to provide a copy of the slides she used for her presentation so they are attached at the end of this newsletter.

In the Q&A time after her talk, Dr. Albayda clarified some issues that have puzzled some of us. For example, she indicated that now there is some support that statins do trigger myositis and that heart muscle can be affected by myositis. There is a newly-discovered antibody related to IBM. She suggested that IBM patients might want to include Co-Q10 and Creatine supplements in their daily regimen. When asked about foods to avoid or include in our diets, she said that we should avoid sprouts, heavy garlic (like eating roasted garlic cloves on toast) and melatonin (a sleep aid).

In addition, during her visits with our breakout groups after the meeting, Dr. Albayda addressed the question of exercise for myositis patients, particularly those with IBM. She is a believer in exercise, including aerobic, resistance and stretching. The article attached at the end of this newsletter provides the results of a study (admittedly small, but significant) which bears out this position.

She also spoke a bit about a fourth myopathy: Immune mediated necrotizing myopathy which did not apply to those of us at the meeting but that may be applicable to others in our KIT. All in all, it was a very informative, understandable and appreciated presentation. We thank TMA for covering Dr. Albayda's expenses.

**TMA Annual Patient Conference in Reno Nevada
September 4-7, 2014
Peppermill Resort, Spa and Casino**

At the KIT meeting, it appeared that very few of us plan to attend this year's conference. If you haven't yet decided, please visit TMA's website for details and don't forget early bird registration ends May 31. TMA will again offer financial aid for members having difficulty paying for registration and the hotel. Watch your e-mail and plan to apply if you would like the help. Conversely, if you'd like to help TMA fund these 'scholarships', contact Bob Goldberg at TMA and he'd be happy to discuss your donation.

Keeping In Touch With Our Members

As always, we circulated cards for members unable to attend for health or other reasons. They include: We celebrate **Joanne Carnevale's** successful back surgery and hope she continues to get stronger. **Penny Andrea-Einmo** has been struggling with leg lesion issues and is undergoing hyperbaric chamber treatments (not easy when you are claustrophobic!) **Claire Gardiner's** husband John has lymphoma and she's his caregiver in addition to managing her own DM. **Ernest Spiva** has fluid around his heart and is unable to travel to our meetings (they live in the panhandle). **Jack Walsh** has fallen a few times and has broken a rib. **Sandi Rocha** has been in rehab to help her get over another broken leg, suffered in a fall. In addition, we offer our condolences to **Jeanne Foster** whose husband Bob recently passed away from cancer and **Elaine Meyer**, whose husband Carl had a cerebral hemorrhage and also has passed away. These and all members are in our prayers. Please let me know if you or another member is hurting or for that matter, has a reason to share celebratory news.

To all our 'snowbird' members, Godspeed as you return to your northern homes. Please keep in touch with us and we look forward to your return in the fall!

Doctor Referrals

We continue to develop our list of doctors in your area, whom you would recommend to your friends. It doesn't matter if they are treating your Myositis or other medical issues. I often get calls from members or newly diagnosed patients asking if I can recommend a doctor in their area. While TMA keeps a list of doctors, there's nothing like a local recommendation. If you would like a copy of the list, please contact Marianne. (The list was provided with our February newsletter).

TMA's Video Library Continues to Grow

At our last meeting, Penny was kind enough (and talented) to video tape the Caregiver Conversation skits we developed. We sent them to TMA and now these skits are on TMA's website for other KITs to use and enjoy. In addition, there are now eight new skits demonstrating some myositis-oriented Exercise. These are the creation of Jim Berg, a newly-diagnosed IBM patient who is determined to keep as much muscle strength as possible. Please go to TMA's website to view these and other videos.

What's an "Elevator Speech"?

In our breakout sessions, it was suggested that we consider developing an elevator speech for the next time someone asks one of us (patient or partner) about our myositis disease. For those unfamiliar with the term, in the business world today, managers are expected to have a very brief 'speech' about what they want to say if they are ever on an elevator with their company's CEO. In the April-May edition of IGLiving Magazine, an article pointed out how important this skill could be for us as well. After all, if you are at a party, walking out of church or just happen to run into a friend you haven't seen since you were diagnosed, what do you want to tell them in a brief conversation that will keep their attention and get across your point? The article suggested the following tips.

- Ask before you explain: say for example, "I have Polymyositis; are you familiar with it?" This avoids you giving more information than they need.
- Don't get too technical: Your latest CK is important to you but what they want to hear is that you are having difficulty getting up from a chair or doing your normal housework activities.
- Use analogies: Acknowledge that you may look 'normal' but like a diabetic, you have serious health issues.
- Mention what you can do: this helps avoid appearing to be asking for sympathy or pity.
- Keep it short! "This is what I have; here is how it affects me, now let's go to lunch".

Our groups had a chance to discuss what we tell our friends and to share how we do it. What's your speech?

Team Tommy News

We heard from the two ladies who started the Team Tommy Foundation in memory of their husband/brother, Tommy Worthington who died of DM. They plan an upcoming fundraiser selling a 2015 Guns and Hoses Calendar showcasing local firefighter and police heroes. Contact them for details at info@teamtommy.org Also; their foundation can provide financial assistance of up to \$500 for people with myositis.

What Makes Our KIT so Successful?

It's our people! Each of our meetings and activities is the result of the efforts of many people. We always have a sign on our refreshment table thanking those who have helped that day but there are more. So just in case no one has said it lately, your KIT leaders of Barb, Donna, Rose and Marianne are very grateful for everyone's help. This past meeting, Matt, John, Jim K, Bernie and Karen all contributed. In addition, at least four people lugged coolers, ice and drinks and another four brought desserts to share. These may seem like small contributions but imagine a meeting without chocolate! Or without bottled water or a working projector or microphone. It all goes to help each meeting be the success it is.

If you didn't get to sign up to help with drinks or desserts, please do. We know not everyone can help at every meeting but if you're willing to be on the list to be contacted, please let Bernie know for drinks (jcarnevale@tampabay.rr.com or 813-891-1885) or Karen Jacobs for dessert, (kejacobs@verizon.net or 941-360-9889). And again, thank you to all who make our group so special.

August 2 Marks our Seventh Anniversary Meeting!

Plan to attend our celebration of seven years of our KIT (there WILL be cake from a new baker). Our speaker will be a Pharmacist who will address myositis meds and what we need to know about them and their interaction with all the other 'stuff' we take. See you August 2. Till then, have a safe summer!